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The equity turn in palliative and end of life care research: Lessons from the poverty literature

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Abstract

Palliative and end of life care researchers are being issued
'wake up' calls that they need to start adopting an equity
framework and pay more attention to how the social deter-
minants of health impact people at the end of their lives.
Acknowledging systemic health inequities has become even
more important during the COVID-19 pandemic. I argue
that within this new equity-driven agenda, learning needs
to be incorporated from decades of work within critical
poverty studies which critiques the very concept of poverty.
I highlight the most relevant of these critiques and advo-
cate for the transfer and translation of these arguments into
palliative and end of life care research by scholars working in
the field. Just as poverty studies was critiqued in the 1990s
for theoretical weakness and an uncritical empiricism, so
palliative care and end of life research needs to go beyond
its almost exclusive concentration on *measurement* to show
a deeper awareness of, and even a commitment to chang-
ing, the structural context within which people are dying.
I argue that just as critical poverty scholars and primary
care researchers have argued for a fairer political-economic
system, so palliative and end of life researchers need to not
only 'wake up' but also 'stand up' and become more political.

1 | INTRODUCTION

Discourses about the social determinants of health have recently been filtering through to those who research care of the dying. Researchers and policymakers in the fields of palliative care and death studies have been issued with a 'wake up' call that they need to commit to an equity-informed agenda and undertake to research and address the social determinants of dying (Gott, 2021; Hussain et al., 2021; Reimer-Kirkham et al., 2016; Stajduhar, 2019).[1] In the UK, it was the 1980 Black Report that critically exposed the fact that people's socio-economic circumstances are the largest determinant of their lifetime health, including their life-expectancy (Department of Health and Social Security, 1980). Subsequent reports by the Institute of Health Equity (Marmot, 2010, 2020a) and the World Health Organisation (2008) have come to the same conclusion: that health inequalities arise from a complex interaction of many factors unrelated to the provision of healthcare, including: income; housing; education; social isolation; and disability, all of which are determined by a person's economic and social status in society, and often determined before they are even born (Marmot, 2010, 2020a).

During the COVID-19 pandemic, the socio-economic gradient in health in economically advanced countries has become even more obvious (Evans et al., 2021). COVID-19 infection and mortality rates have been shown to be significantly higher in areas of higher deprivation, the intersecting reasons for which are examined in the latest Marmot report (2020b). The COVID-19 public health crisis is also the greatest social and economic crisis since the Second World War and more people are finding themselves struggling financially as a result (Social Metrics Commission, 2020). The crisis has also coincided with the rise of social movements – most notably the Black Lives Matter movement - calling for political action to address the long-term structural inequities experienced by people who experience racism.[2] In economically advanced countries, race and ethnicity commonly intersect with socio-economic inequality and therefore inequities in health (Phelan & Link, 2015). There is a sense that the potential worsening inequities which may result from the pandemic in terms of lifetime health disparities between those struggling to get by and those living more affluent lifestyles can no longer be ignored. Critical commentators argue that the pandemic provides a once-in-a-generation opportunity to reimagine society and push for a fairer redistribution of power and wealth (Goldin, 2021; Marmot, 2020b; Younge, 2021).

Death and dying feature in the health equity debate in two ways. First, people who are more socio-economically disadvantaged are likely to live with a higher burden of disease (multi-morbidity) and, ultimately, to die younger. In Scotland,[3] for example, the gap in healthy life expectancy at birth between the poorest and richest areas is 25.1 years for men and 21.5 years for women (National Records of Scotland, 2021). Second, there is evidence of socio-economic inequities in terms of access to both specialist and generalist palliative care. A person living in a more deprived area is less likely to receive hospice care, is more likely to be admitted to hospital in the last 3 months of life, often as an emergency admission, and after their death their relatives are less likely to report that they were satisfied with the care they received. In sum, people living in more deprived areas in economically advanced countries may have less opportunity to meet the cultural markers of a 'good death'. Evidence of these inequities, as well as the increased political attention on the social determinants of health, has precipitated an 'equity turn' in palliative care and death studies research.

The aim of this article is to reflect on how the critical poverty studies literature can inform this 'equity turn'. The term 'equity' differs from 'equality' in that it indicates fair distribution according to need, rather than equal distribution potentially *not* according to need. According to the World Health Organization (2008), equity is a concept 'based on the human-rights principles of social justice and fairness … and addresses the unfair and avoidable differences among social groups with an aim of achieving more equal outcomes.' The equity turn in palliative and end of life care

involves paying attention to all the ways in which people's access to or experience of end of life care is impacted in avoidable, unfair and unjust ways as a result of colonialism, racism, sexism, homophobia, ableism, all of which intersect with poverty and deprivation (Rowley et al., 2021). A recent intersectional analysis of policy initiatives to encourage home dying in British Columbia, Canada, for example, revealed that home is a highly contested site for palliative care with the house/home/family often conflated and policies 'based on an ideologically laden perspective where families are seen as white, middleclass, heterosexual and nuclear' (Hankivsky et al., 2014, p: 8).

In this article, I focus specifically on poverty and deprivation, all the while acknowledging that discrimination and structural disadvantage are intersectional (Collins & Bilge, 2016). I refer to poverty and deprivation both jointly and separately throughout as they are sometimes used interchangeably in the literature, and sometimes connote different things. As poverty scholar Paul Spicker (2007, p: 34) points out, there are not many senses of poverty which do not involve deprivation in some form. Of note here is that the words used to denote poverty and deprivation may have different meanings and associations for people, particularly those with lived experience of financial and material hardship, something poverty scholarship has been keen to attend to and therefore has useful insights to be shared with other disciplines.[4]

In focussing on the critical poverty literature, I highlight the most relevant debates and critiques and advocate for the transfer and translation of these arguments into palliative and end of life care research in order to: (1) prevent knowledge becoming siloed between critical social science which is theoretically-driven and healthcare research which tends to be more empirically driven and (2) to ensure that research is designed and carried out in the full knowledge of such critiques to avoid empirical pitfalls and conceptual fallacies, some of which I highlight in this article. Finally, I argue that just as critical poverty scholars are reflexive about and incorporate their own ideological standpoint into their research, often arguing for greater redistribution and a fairer political-economic system, so palliative and end of life researchers need to not only 'wake up' but also to 'stand up' and become more political, for example, in the way primary care research has become. Afterall, learning from primary care, which delivers the bulk of generalist palliative care, would seems opportune. Poverty studies itself was critiqued in the 1990s for theoretical weakness and a blinkered empiricism (Novak, 1995). Palliative care and death studies researchers can learn from this and challenge the current empiricist framework and preoccupation with the *measurement* of socio-economic disparities, and instead provide stronger theoretical direction and a deeper awareness of *the socio-political context* in which people are dying (Reimer-Kirkham et al., 2016, p: 300).

I approach this issue from an anthropological perspective, in the sense that I want to historicise and contextualise the current 'equity turn' in palliative and end of life research, while also being reflexive of my own position within the field (Herzfeld, 2001). I characterise myself and my research as being a part of this drive for increased attention on issues of social equity and the theoretical critique presented in this article stems from my position within these debates and from conducting empirical research (with theoretical import) in this area in the UK. As I write, I am leading a qualitative study into how poverty and deprivation influence end of life experiences in Scotland, a study I would categorise as part of the 'equity turn' (UKRI, 2019). In the classic anthropological sense, I have both insider and outsider status. I am embedded within, and aim to contribute to, equity-informed palliative care research, while at the same time my non-clinical/social science background provides critical analytical distance from the field of study.

2 | HOMES FOR THE 'DYING POOR' IN THE UK

Given the current criticism levelled at palliative care policy that it too often assumes a stably housed, white, middle-class, male patient (Gott et al., 2020; Hankivsky et al., 2014; Stajduhar, 2019), it is easy to forget that the original palliative care patients were actually the 'dying poor' who were dying of Tuberculosis and cancer in the late 19th and early 20th Century. Many of the original 'homes for the dying' – considered proto-hospices (Goldin, 1981) - were set up in northern Europe (countries like Ireland, France and the UK) around this time and had the specific remit to offer accommodation for the 'dying poor'. Indeed, many of the homes even included this remit in their title, for example,

'St Luke's Home for the Dying Poor' in London. These homes, predominantly founded and organised by women (Clark, 2014), were charitable philanthropic ventures rooted in a strong religious tradition focused on saving souls on the deathbed (Clark, 2016, p: 36). In this sense, the health equity turn in palliative care research actually returns care of the dying to its historical roots.

Of further interest is what the historical record shows about how patients' morality was judged prior to admission to the homes. Humphreys' (2001) historical account of three homes in London reveals that a distinction was made between those judged 'deserving' and those judged 'undeserving', with beds only offered to the former. This distinction stems from the U.K's New Poor Law of 1834 whereby the state only offered financial support in the community to those judged to have fallen on hard times for 'respectable' reasons like sickness, disability or old age. Those who were otherwise able-bodied but in need of financial support for other reasons such as alcoholism, or who were judged as criminal or immoral, were sent to institutional workhouses where conditions were kept deliberately bad in order to act as a deterrent. At the end of the 19th and early 20th Century, those judged 'undeserving' would have no option but to die in the workhouse infirmary, barred from the new proto-hospices because of the perceived threat of moral contamination and perhaps because such people were considered less amenable to a deathbed conversion to Christianity.

Discourses of poverty, which I will turn to later in the article, are still informed by the 'deserving' and 'undeserving' distinction, which was transported from Victorian Britain to the New World in the early part of the 20th Century where they continued to shape attitudes and policies towards people experiencing poverty. In relation to palliative and end of life care, the historical record shows that while poverty was a focus for the emerging end of life specialism, moralistic judgement was executed to establish limits on who could receive this new specialist form of care. The female leaders who spearheaded compassionate care of the 'dying poor' were still judging and categorising their patients according to their perceived 'deservingness' or 'Godliness' as well as their ability to fit into the pre-existing model of care.

3 | INTEREST IN POVERTY AND DEPRIVATION FROM PALLIATIVE AND END OF LIFE CARE

In this section, I analyse some of the evidence of disparity in end of life care provision which has given rise to the 'equity turn' and raised the profile of the social determinants of health when it comes to care of the dying. I also put the equity turn into historical-political context and offer a view on why it has arisen at this particular point in time.

Despite an early focus on caring for the 'dying poor', over the years since, both palliative care and death studies have been accused of being blind to the issues affecting more multiply disadvantaged, less 'middle class' patients. Stajduhar (2019, p: 2), for example, suggests that a 'typical' patient admitted to a palliative care unit holds various privileges in terms of being housed, white, having the support of (biological) family and a strong social network; and having the financial resources to pay for supplementary care and other costs at the end of life. For Stajduhar (2019, p: 3):

> people who live in poverty and who are otherwise made vulnerable by the structural conditions in which they exist *are almost invisible* in modern day hospice and palliative care, at least in the Global North (my emphasis).

Back in 2007, Glennys Howarth offered an adjacent critique of how working-class deaths had been ignored by sociologists of death. She postulated three reasons for this: (1) that social class as a category of social organisation and identity in itself had fallen out of favour among social scientists; (2) that death studies was too isolated or siloed from the conceptual concerns of mainstream sociology such as social class; and (3) that academics working in the

death studies field tend to be middle-class and therefore the 'emotional template' on which their studies are based reflects the middle-class worldview of their authors:

> When it comes to the engagement with death, the expression of emotion and the development of ritual is, for the most part, based on middle-class norms such as the importance of verbal communication [...] and control and individualisation of funeral and mourning rituals (Howarth, 2007, p: 430).

Howarth's view was not that sociologists who work in the field were not interested in inequality, but that the ritual and emotional experiences of 'working-class communities' (her term) tended to be ignored in favour of victim narratives (and to this I might add pity narratives or philanthropic narratives).

Conway (2012, p: 448), picking up the baton from Howarth, agrees that 'unwittingly, sociologists of death are in danger of engaging in symbolic violence which maintains middle-class and upper-class privilege and advantage.' What Howarth terms a middle-class 'emotional template', Conway (2013) calls the 'middle-class aestheticisation' of dying, death and grief practices in which middle-class tastes, behaviours and dispositions are presented as being universally relevant and the 'norm' by which the practices of other social classes are judged or, because they don't conform, are simply not seen.

Both critical palliative care and death studies scholars, then, have identified an invisible privilege which underpins research in this area, in terms of both the typical palliative care patient and the typical death studies scholar. This speaks to a need, identified in the more recent equity-driven agenda, to become more reflexive in terms of 'othering' practices, the cultural appropriateness of palliative care, and in thinking about *who* is setting the research agenda (Anderson & Devitt, 2004; Rowley et al., 2021; Stajduhar, 2019). This includes acknowledgement that palliative and end of life care researchers are disproportionately white and from high-income countries (Hussain et al., 2021; Seale, 2010).[5]

As I will discuss in the next section, qualitative, participatory approaches which try to capture the worldview of people with lived experience of poverty and allow *them* to influence the research agenda, offers one way to counteract some of the invisible privilege held by researchers. While enabling participation can be challenging with people who are dying and who therefore have waning energy levels and may be wary of committing to a research project which will take up some of the limited time they have left, it has also been shown to work in terms of offering validation and/or therapeutic benefit (Bellamy et al., 2011; Bloomer, Hutchinson, Brooks & Boti, 2018). Similarly, encouraging diversity in the research workforce and a reconsideration of the models of care on offer to those at the end of life are other ways to open up the field.

Around the same time as this privileged gaze and the lack of visibility of those experiencing structural marginalisation were becoming the subject of critique within palliative care and death studies, there were also influential quantitative studies published which evidenced clear socio-economic inequities in terms of both access to both specialist and generalist palliative care. The first issue which appeared on researchers' radars was disparity in terms of dying at home, which for a long time has been a focus of palliative care policy in high income countries (Robinson et al., 2016), although more recently this has been problematised from various angles (c.f. Hankivsky et al., 2014; Hoare et al., 2015; Robinson et al., 2016). Studies have consistently shown that people from areas of higher deprivation are less likely to die at home or in a hospice and more likely to die in a hospital (Gao et al., 2013; Higginson et al., 1999; Raziee et al., 2017; Sleeman et al., 2016). People living in more deprived areas or with lower socio-economic position (measured in a variety of ways – see later discussion of Davies et al., 2019) also fare worse on other population-level 'quality indicators' for good end of life care, such as receiving specialist palliative care and avoiding hospital in the last months of life (Henson et al., 2015; Sleeman et al., 2018).

In terms of generalist palliative care provided in the community, the 'inverse care law', as it is known, undoubtedly has an effect. This law, first identified in the 1970s, encapsulates the idea that a person living in a more deprived area has, on average, greater primary care needs than a person living in a less deprived area (because of a higher incidence of multi-morbidity), but their general practitioner (GP) has less ability to meet those needs for a variety of reasons

(Hart, 1971; Mercer et al., 2021). This 'law' can affect generalist palliative care delivery as well, which forms the bulk of end of life care in many economically advanced countries (Fisher et al., 2016; Shipman et al., 2008). Further evidence of lower quality end of life care comes in the form of surveys with bereaved relatives. The 'Voices' survey in the UK, for example, found that ratings of fair or poor quality care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%) (Office for National Statistics, 2016).

Without a doubt, the evidence base showing that socio-economic disparities persist at the end of people's lives in terms of the care received and perceptions of that care has been steadily building over the last 20 years. A systematic review by Davies and colleagues in 2019 showed definitively that there is a clear social gradient operating across all population-level quality of death indicators in high-income countries. However, I argue that interest in socio-economic inequalities has accelerated recently into what I identify as a demonstrable 'equity turn' within the specialism, rising up the policy and research agenda and incorporating intersecting inequities. The reason that the spotlight has fallen on this issue now is because the social determinants of health more generally have been rising dramatically up the healthcare agenda. Evidence has consistently shown that the social gradient is extensive and persistent and also growing (Marmot, 2020). This is a result of many governments around the world introducing austerity measures in response to the 2008 global economic crash, reducing public expenditure and cutting back on services known to reduce health disparities (Blane & Watt, 2012). If the fundamental building blocks of health are, for example, having adequate housing, good nutrition and opportunities to participate in society, all of these can be affected by cuts in public services. This trend towards a tightening of public expenditure will likely accelerate further in the aftermath of the COVID-19 pandemic as countries seek to reduce the phenomenal amounts of debt which they have accrued during the crisis.

The overwhelming evidence about the persistence and worsening of health inequalities has 'woken up' policy-makers and researchers whose focus is specifically on the end of life (in the UK context see e.g., Marie Curie, 2020; All Party Parliamentary Group for Terminal Illness, 2021). However, the 'equity turn' is not entirely driven by the evidence. It is also driven by where the political 'heat' is, where funding is being allocated, as well as by researchers' own commitment to a social justice agenda and perhaps even a desire to make reparations for previous blindness to the issue or for perpetuating a privileged gaze (Hussain et al., 2021; Reimer-Kirkham et al., 2016). I will come back to these points at the end of the article. What is clear is that the equity turn has arrived and although there are echoes of palliative care's roots and the care of the 'dying poor' in the proto-hospices of the early 20th Century, the emphasis now is on building a strong evidence base and developing equity-promoting interventions.

4 | PREOCCUPATION WITH MEASUREMENT

In order to build a strong evidence-base, the existence and severity of the socio-economic equity gap needs to be *proven* via measurement. An empiricist framework focused on quantification has thus come to dominate the field. This is also influenced by the biomedical positivist paradigm towards which palliative medicine, as a clinical specialism, is orientated, keen to win recognition and parity with other clinical disciplines (Clark, 2002). But when it comes to measuring socio-economic disparities and inequities, there has been considerable variation in terms of *what* is being measured and *how* it is measured.

In their systematic review on the influence of 'socio-economic position' on use of healthcare in the last year of life, Davies et al. (2019) found that in the 209 studies which they included in their international review, a total of 273 different measurements of socio-economic position were used. They categorise these as measurements of: area deprivation; education; income; (healthcare) insurance; occupation; housing; social class; and literacy. Area-based measures dominated in the studies reviewed, followed by measures of education. Of the 209 studies reviewed, 27 were specifically focused on the influence of socioeconomic position, but in only 12 of these studies was any theoretical justification provided for the researchers' choice of measure (Davies et al., 2019, p: 8).

In the poverty literature, a lack of theoretical justification would, these days at least, be considered poor scholarship. In key texts on poverty, explicit and repeated emphasis is given to the conceptualisation-definition-measurement triad and the need to present a clear conceptualisation and definition of poverty and deprivation before progressing to measurement (Lister, 2004; Spicker, 2007). However, this has not always been the case. Poverty research has also historically been dominated by a preoccupation with measurement (Harriss, 2009; Novak, 1995). According to Novak's (1995, p: 58) critique in the 1990s, poverty was being studied 'from within the prism of a cramped and atheoretical empiricism' with measurement viewed as a substitute for analysis and explanation. Various critiques were mounted by Lister (2004) and Novak (1995), among others, which forced a critical appraisal of the state of the field and ushered in a new dawn of critical, reflexive poverty researchers who were keen to develop social theory and engage in more participatory methods. Scholars researching poverty in more economically advanced countries were heavily influenced by debates going on in development studies and research in the global South (see e.g.: Chambers, 1988). There followed widespread acknowledgement that poverty was fundamentally a consequence of social relations rather than a *thing* to be attacked:

> Focusing on social relations highlights the centrality of the actions and strategies of rich and poor alike in determining poverty outcomes, and the quality of the embodied experience of deprivation (Green, 2006, p: 1124).

Returning to the fundamental conceptualisation-definition-measurement triad, Lister (2004, p: 4) explains that conceptualisation is about *meaning* - for example, 'lack of basic security' – as well as about how people *talk about* and *visualise* poverty. Historically, and to some extent still today, meanings of poverty have been influenced by politics, the media, and academia. They have been influenced far less by people with lived experience of poverty. Definitions are more precise than concepts and have to distinguish the state of poverty from that of non-poverty. The narrower the definition, the easier it is to *operationalise* in terms of developing a measure. It goes without saying that broader definitions encompassing the relational/symbolic aspects of poverty, such as feelings of shame and stigma, can be harder to develop objective measures for but doesn't mean that they are less important in determining the experience of poverty (Lister, 2004, p: 4).

The final arm of the triad is measurement. But measures are always just proxies, used to reflect conceptualisations and definitions. Income based measures of poverty have been dominant in Europe for many years[6] (ONS, 2019). More sophisticated area based measures of multiple deprivation have been developed since the 1980s and these are based on a multidimensional concept of relative poverty and deprivation which includes non-material aspects (Nolan & Whelan, 1996). There are also more subjective measures of poverty: asking an individual what they deem to be an essential level of income to run a household such as theirs, and where they think they sit in relation to that threshold (Bradshaw & Finch, 2003). Socio-economic *position* is also measured in a variety of other ways, and I listed the various measures identified by Davies et al. (2019) in their systematic review of the effects of socio-economic position on healthcare usage at end of life earlier in the article.

All too often, however, the triad breaks down and measures get divorced from concepts and definitions, as was the case for the 12 palliative care studies identified by Davies et al. (2019). They become theoretically unmoored. This has the effect of removing the very meaning which supports use of the measure, by divorcing it from the cultural, political and economic context in which poverty and deprivation are actually experienced and understood by people. To highlight the importance of the concept-definition-measurement triad, Bradshaw and Finch (2003) examined how different measures, based on different concepts and definitions of poverty and deprivation, actually generated very little overlap in terms of the people who were identified: 'the people who are defined as living in poverty by different measures of poverty are different' (Bradshaw & Finch, 2003, p: 523). This leads to the radical realisation that depending on how poverty and deprivation are conceptualised an entirely different policy response would be required and a different political question asked.

In palliative and end of life care research, as in most healthcare research, relative area-based measures of deprivation are the most commonly used measures when researching socio-economic health disparities/inequities. It should be noted here that the term 'deprivation' has come to be most commonly associated with area-based measures that are used in a number of countries. As a lay term, however, deprivation is considered no less stigmatising than the term poverty. These measures are complex 'composite' measures based on ever more sophisticated indices (Clelland, 2021). Despite the radical effort to move beyond arbitrary and crude income measures and embrace a more multi-dimensional concept of poverty and deprivation, area-based indices have also been critiqued. First, the formulae and method of calculation is a constant topic of debate (Atkinson, 2003). Second, area measures are subject to the ecological fallacy: the assumption that people residing in the same area all share the same deprivation profile, which they don't. And third, relative deprivation is measured against various social norms which relies on a hegemonic perception of 'standard of living', viewing deprivation in terms of deficit and affluence as the invisible norm (Fu et al., 2015). In their Foucauldian analysis, Fu et al. (2015) stress that it is those with power and privilege in society who get to define a 'customary' standard of living and the subsequent measures of poverty and deprivation derived from that norm.

It is also widely recognised that implicit in definitions of poverty are explanations for the existence of poverty. In other words, whether the responsibility for the existence of poverty lies with individuals or with the political-economic structures of society. For example, in 2016, a newly elected Conservative Government in the UK (ideologically neoliberal) effectively scrapped the Child Poverty Act 2010, which had contained requirements to reduce income poverty, and replaced it instead with measures of household 'worklessness' and educational attainment at 16 (Stewart & Roberts, 2019). These new targets were in line with an ideological emphasis on individual failings rather than structural determinants, such as the availability of jobs or 'poor work' – work that fails to take people far enough away from poverty (Byrne, 2005). Unequivocally, how poverty is measured is highly political.

In sum, we might want to think that rates of poverty or how comparatively deprived an area is a matter of 'objective' social scientific measurement, but this is simply not the case, and this fallacy has been exposed and critiqued within critical poverty studies since the 1990s. Critical social science has a long history of asking 'whose definitions count, who makes the rules and whose voice is being heard' and has an important role to play in the pursuit of stronger more responsive health systems (Greenhalgh, 2018, p: 2). Palliative and end of life care researchers need to develop greater awareness of such critiques and recognise that political and ideological assumptions - and potentially the privileged worldview of researchers themselves - are embedded in conceptions of poverty and the measures derived from them. Crude empiricism decontextualises poverty, erasing vital recognition of the political and economic structures which give rise to it.

5 | THE CONTENT OF THE CATEGORY OF 'POVERTY' IS NOT SELF-EVIDENT

While it is governments which ultimately get to decide who is considered 'poor' there is also a vast array of institutions established to describe, locate and quantify poverty. This is the case in both the international development sector (Green, 2006) and in the poverty alleviation sector in more economically advanced countries.[7] As Green (2006, p: 1110) argues, these institutions all want to attest to the facticity and tangibility of poverty through empirical quantification (as outlined in the last section). But what all these efforts at measurement reveal is not so much the magnitude of the issue but the power of those institutions to make it visible. In Green's (2006) analysis, poverty alleviation organisations *themselves* bring the category of 'poverty' into being.

In this Section, I want to explore the literature about another important group which has views on what poverty is and the reasons for it: those with lived experience of poverty and deprivation. Thus far, such perspectives have very rarely featured in palliative and end of life care research. One might imagine that this group would be the best placed to attest to the facticity and tangibility of poverty. However, the social science evidence suggests otherwise and self-identification is reported to be low. According to Shildrick and MacDonald (2013, p: 301), the shame and stigma

associated with the condition of 'being poor' means that even people experiencing deep and persistent poverty will do everything they can to 'distance themselves from the stigma of poverty and the shame of 'welfare dependence.' People experiencing poverty are subject to the same social and political pressures as others to pathologise the condition of 'being poor' and to believe the 'poverty propaganda' perpetuated by governments and the media[8] (Garthwaite, 2016; MacDonald et al., 2014; Shildrick, 2018).

Poverty propaganda (Shildrick, 2018) works by disseminating pernicious 'zombie' arguments (arguments that are disproved again and again but constantly revived) about out-of-work benefit claimants living comfortable, even desirable, lifestyles of choice, preferring to 'scrounge' off the state rather than work for a living. Neoliberal ideology views responsibility for poverty residing with the individual and to be a result of people's 'character-personality defects' (Margaret Thatcher, 1978, cited in Jones, 2012, p: 64) such as being 'work shy' or showing bad money management. Meanwhile, deep-seated structural inequalities or supply-side issues in the job market are downplayed or denied. Within this worldview, the very existence of poverty can be questioned and therefore supressed as a political issue. Those who experience the day-to-day indignities and traumas of struggling to get by on a low income are often left without a political voice, not through active silencing or censorship, but rather through hegemonic discourses whereby ruling ideas denying the existence of 'real' poverty come to dominate leaving little space for people to claim a political voice or mobilise collectively (Freire, 1970; Shildrick & MacDonald, 2013).

Poverty researchers and UK advocacy organisations have argued for the need to reclaim the 'p' word, as Lister (2004) calls it, despite the baggage that comes with it, in order to resist the hegemonic narrative that poverty and deprivation don't exist or only in very small pockets (see e.g., Joseph Rowntree Foundation, 2021). Calls for a renewed politics of redistribution or a new politics of representation which doesn't Other those experiencing economic hardship but rather gives space for them to name and define their own experience are becoming louder as the COVID-19 pandemic wreaks economic devastation globally.

A participatory praxis in poverty research and a demand to amplify the voices and words of those with embodied experience of poverty have been viewed as possible ways of challenging the status quo for some time now (Boone et al., 2019; Joseph Rowntree Foundation, 2020). While in academia it remains the norm that those who write about and talk about poverty are themselves affluent and removed from the experiences they are analysing or theorising (Lister, 2004, p: 2; Shildrick, 2018, p: 10), there have been some attempts to produce immersive in-depth qualitative studies in order to counterbalance the prevalent quantitative focus on measurement (Krumer-Nevo, 2005). For Fu et al. (2015, p: 227–228), while the quantification of deprivation is 'an invaluable tool to highlight inequality' it can only provide a 'two-dimensional map'. In order to provide more three-dimensional understanding, qualitative research which understands the value of narrative and prioritises the life of the person experiencing material hardship and symbolic violence is required. Participatory and action research methods in particular are approaches from within critical social science which can have a role in using collectively produced knowledge to help develop critical consciousness in marginalised groups (Greenhalgh, 2018). Colleagues and I have made a plea for more participatory, qualitative research into experiences of poverty and deprivation specifically at end of life (Rowley et al., 2021). My point here is that whatever new research is carried out needs to be embedded in prior learning within the critical poverty literature, which underwent its 'participatory turn' some decades ago and has allowed time for debates about the politics of representation to mature through layered critique.

6 | POLITICISING PALLIATIVE CARE AND DEATH STUDIES RESEARCH ON THE SOCIAL DETERMINANTS OF DYING

Palliative care, with its core focus on quality of life and attending to multi-dimensional sources of pain, has long had a mandate to take seriously the social determinants of health. Indeed, the original conception of 'total pain' included 'financial pain', which acknowledged that financial hardship and insecurity can contribute to the multi-dimensional experience of pain at the end of a person's life (Mount et al., 1976). The concept of 'complexity' has emerged recently

in palliative and end of life research, which appears to be an attempt, in part at least, to acknowledge the social determinants of health and build up a conceptual framework specific to end of life care (Finucane et al., 2021; Hodiamont et al., 2019). Pask et al. (2018), for example, discuss how complex cases can be determined by pre-existing complexity, for example, 'long-standing difficulties with finances and/or housing', as well as cumulative complexity, which could be multiple and chronic hardships experienced across the lifecourse. While the concept of complexity has the potential to incorporate discussion of the social determinants of health, my view is that it is an overly-medicalised term which defaults to a depoliticised conceptualisation of symptom complexity, negating a more politicised reading of the societal conditions which engender pre-existing, cumulative or even 'invisible' complexity (Pask et al., 2018).

Similarly, while the equity turn in policy-circles shows a valuable engagement with the social determinants of dying, there is still evidence of some deficit framing in terms of its approach to models of care and what are considered as 'customary' ways of living (Fu et al., 2015). A recent report by the UK Parliament's cross-party group on Terminal Illness, for example, discusses 'homes which are not conducive to providing good quality palliative care' (2021, p: 7), and that 'providing good quality palliative care in unsuitable home environments can be almost impossible' (2021, p: 8). While the deficit framing may not be explicit, such inflexibility in the service-model of palliative care holds an inbuilt assumption of norms and could hardly be considered responsive or caring for patients 'where they are at'. Palliative care models will need to be re-evaluated for their cultural appropriateness if equity-focused practice is going to become mainstream (Hussain et al., 2021; Stajduhar, Giesbrecht, Mollinson, Dosani, & McNeil, 2020).

Palliative care as a specialism has many crossovers and synergies with primary care, not least that primary care clinicians are meant to deliver generalist palliative care (Quill & Abernethy, 2013). A number of primary care researchers have been strong advocates for increased funding and research into the social determinants of health (Moscrop et al., 2020). As part of this, there have been initiatives to widen access to medicine for applicants from more socially diverse and disadvantaged backgrounds (Blane, 2018) and calls for enhanced training which develops doctors' 'structural competency'; in other words, which deepens their understanding of the structural drivers of poor health (Metzl & Hansen, 2014). There are also instances of primary care researchers not shying away from taking a more political stance and explicitly lobbying governments about health damaging austerity measures (Blane & Watt, 2012; Mercer et al., 2021).

As I reach the end of my argument, I contend that palliative and end of life care has the potential to become much more politicised in the same way that primary care has done. To be clear, I am not advocating for more research into 'complexity'. What I am advocating for here is that palliative care and death studies researchers take into account in a more fundamental way the wider political, institutional, and economic conditions in which (1) healthcare is delivered and (2) poverty comes to exist (Jensen et al., 2021). Together with colleagues, I have elsewhere provided a detailed list of policy, practice and research recommendations (Rowley et al., 2021). To charges of mission creep or warnings about the dangers of ideological bias infiltrating research, I respond by arguing that to incorporate critique of the political-economic systems that distribute power and resources in a society will actually *better* contextualise the research which is being conducted and move away from the idea that poverty is a social aberration rather than built into our societal systems (Harriss, 2009). A more consciously theorised *and* politicised field of research will help to re-establish the link between concept-definition-measurement and make research in this area more meaningful through an acknowledgement of the root causes of inequities and an overt commitment to building a fairer, more just system.

7 | CONCLUSION

The 'equity turn' in palliative and end of life research is a relatively recent development and research in the field has yet to mature in the same vein as research in poverty studies. As I've argued in this article, when researching poverty and deprivation specifically, the palliative and end of life fields are dominated by attempts at measurement and description with scant reference to conceptual or theoretical arguments which can speak to the broader

socio-political context and what abstract measures mean in terms of real human beings and their embodied experiences. The same could have been said of poverty studies in the 1990s, before the field was shaken up by its own critical turn, and there is much that palliative and end of life care scholars can learn from those debates. It is important to specifically address the lack of qualitative and participatory research required to bring forth a three-dimensional understanding of what it is like to be dying whilst also experiencing poverty and deprivation, in all its multi-dimensional forms. Moreover, there has been an absence of engagement with broader debates about *who* has the power to define the very categories of 'poverty' and 'deprivation' and, indeed, the political context of how people see and define their own situation or the societal structures which create inequalities in the first place.

While researchers and practitioners are obviously not *required* to take a political stance, the increasing inequalities across many societies, which are likely to be further exacerbated by the economic devastation wrought by the Covid-19 pandemic, cannot be ignored. Researchers in the field can help to advocate for more systems-thinking, more intersectional analyses (c.f. Hankivsky et al., 2014) and, ultimately, a more politicised take on what some of the solutions might be. Influential health equity reports in the UK, for example, haven't shirked from advocating for greater redistribution of resources and investment in public services as the only way of closing the health equity gap (Marmot, 2010, 2020a). This is to truly acknowledge that many of the solutions to poor health lie outside of healthcare with the political-economic system. Similar acknowledgement is now required by those practitioners, researchers and policy-influencers who want to improve the end of life experiences of those affected by poverty and deprivation.

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ENDNOTES

[1] The journal *Palliative Medicine*, one of the world's leading journal for the medical specialism, released a call for a special issue on equity-orientated palliative care in 2021, to be published in 2022. https://journals.sagepub.com/page/pmj/equity_oriented_palliative_care

[2] I use this term rather than any other in view of the #BAMEOver discussions and ensuing rejection of the UK Government's term Black and Ethnic Minorities or BAME (Inc Arts UK, 2020).

[3] I choose Scotland here because that is where I live and work and is where my current research project 'Dying in the Margins' is based.

[4] For those interested in a longer discussion about the differences between the concepts of poverty and deprivation, please see my other article: Rowley et al., 2021.

[5] Seale's (2010) study revealed that in the UK, palliative care specialists were somewhat more likely to be Christian, religious and 'white' than other doctors. Given that many palliative care researchers are also involved in clinical work, I have extrapolated from this data that palliative care researchers are also somewhat more likely to be white.

[6] The most common of these is the 60% of median income. For an excellent summary of the critiques of this measure, see Stewart and Roberts (2019, p: 532, 533), section entitled: *60% Median: A Deeply Flawed Measure?*

[7] The poverty alleviation industry has been pejoratively called the 'poverty safari' (McGarvey, 2017) where well-intentioned but misguided outside organisations populated with middle-class activists parachute into more deprived areas and try to engage in philanthropic work which is non-embedded/non-participatory and is viewed by people living in the area as providing little long-term benefit.

[8] These researchers are specifically focused on the UK political-economy but the same theory applies to other economically advanced countries dominated by neoliberal ideologies.

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